Before The Dying Begins

by Giles R. Scofield, J.D.

During the same week that a jury acquitted Dr. Jack Kevorkian of assisted suicide and a federal district court judge in Seattle ruled that the State of Washington's ban on assisted suicide is unconstitutional,[1] I happened to be Denver, discussing local efforts there to establish guidelines about medically futile care. Do these separate events have anything to do with one another? I think so.

It's no coincidence that medical futility and physician-assisted suicide dominate medical, legal and ethical circles as they do. Their emergence as dominating concerns reflects the convergence of several strands of thought. These thoughts themselves emanate from the foundational beliefs of our modern society, which finds itself struggling to deny, suppress, repress--do anything but admit--a basic truth. That truth is this: the belief that human reason can enable us to be the arbiters of fate has turned out to be false.

We have not eliminated ambiguity, uncertainty and contingency from the human condition. Fate--meaning death--haunts us as much as it ever has. Although we can postpone death, we cannot prevent it; medicine has proven futile in this regard. And the quest to conquer death will remain beyond our grasp for so long as we are unable to control precisely how, where, and especially when death occurs.

Unwilling to admit the truth, we struggle to hide it. The move to carve out a "medical futility" exception to the rule of informed consent reflects an effort to conceal medicine's impotence against death, leaving intact the illusion that medicine can do something about death. The move to legalize assisted suicide reflects an effort to subdue death, to make how, where, and when it occurs obey our will. They both represent the last, desperate and dangerous efforts to pursue a set of beliefs about reality that reality itself has proven false.[2]

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For this reason, these movements are best regarded as anomic events.[3] That is, they reflect the fact that the beliefs that form the basis of social collaboration are losing their cohesive force, because they have lost their intellectual coherence and their psychological appeal. Old systems of belief, like old habits, die hard, and are likely to appear their most vigorous just when their plausibility is most threatened. That seems to be the case where we, medicine and death are concerned. To see why this is so, we need to look at these issues, I am sorry to say, one more time.

Assisted Suicide

Assisted suicide supposedly takes the cause of individual self-determination to its logical conclusion. As the argument goes, if we truly believe that individuals have the right to determine how, where, and when they die, then we must "empower" them to make death happen, not wait for it to arrive. The only way to do that is to legalize assisted suicide, so that patients can have the means to accomplish this end. The legalization of assisted suicide would enable patients to act autonomously and doctors to act beneficently. Unless you've got something against liberty or think that a painful death is a good thing, you've got to favor the legalization of assisted suicide. It's that simple.[4]

Unfortunately, it's not that simple. Assisted suicide's apologists have forgotten that "logic relentlessly and inappropriately pursued to its end can... readily lead to destructive results."[5] Let's see what those might be.

To begin with, even if we were to limit assisted suicide to competent, terminally ill adults we would encounter some problems. Physician assessments of competence vary considerably, as do determinations of who is and who is not terminally ill.[6] Such assessments reveal as much about the doctor who's making them as they do about the patient. Given the discretion that doctors possess in this area, we should expect that discretion will be exercised in ways that reflect the beliefs, attitudes, biases and even prejudices that doctors bring to clinical decision-making. There is no reason to suppose that these decisions will be made in ways that eliminate uncertainty, ambiguity or ambivalence from them.

Nor is there any reason to suppose that this right can or will be limited to competent, terminally ill adults. Where decisions to forgo life-sustaining treatment are concerned, it is settled, as a matter of constitutional law, that competent and incompetent patients possess the same rights. The only difference between these two groups of patients is how those rights are exercised. Thus, it is only a matter of time before someone raises a constitutional challenge to an assisted-suicide statute, arguing that a right extended to competent patients cannot be denied to incompetent patients. Even if we might be hesitant about allowing physician-assisted suicide to occur under substituted judgment or best interests analysis, how could we deny it to patients who have supposedly left behind clear and convincing evidence of their wishes? Finally, this right would probably be extended to mature minors and to patients who do not fit the statute's

definition of terminal illness, as has occurred elsewhere in right-to-die litigation.

While it might be nice to believe that all these choices will be knowing and voluntary, it is naive to assume that they will be. The quality of information given to patients varies considerably, as does their ability to appreciate it and the conditions under which they are presented with healthcare choices, especially in a society where access to care is a function of personal wealth. Freedom is more a privilege than a right.[7] Anyone who has closely examined the right-to-die cases knows of those cases where the patient's decision to die was inextricably connected to fears about exhausting personal resources and about being institutionalized in our so-called system of care. If we're supposed to be doing what they're doing in the Netherlands (where assisted suicide technically remains a crime) we ought to be creating a system of health care that is as accessible, affordable, sensible and attentive as the Dutch system is. For some reason, we have no difficulty building new prisons, but we just can't pay for good long-term care.

Of course, all the questions and doubts I've raised with respect to assisted suicide could be made as well about decisions to forgo life-sustaining treatment. I'm not going to pretend that decisions to forgo life-sustaining treatment have a certainty to them that decisions about assisted suicide do not. Indeed, I think that we ought to improve our healthcare system to reduce (we can never wholly eliminate) the pressures that affect how patients view these decisions. Having said that, however, I want to explain why decisions to forgo treatment and decisions to undergo assisted suicide are not commensurate.

In the first place, the right to refuse treatment respects a negative right while the other respects a patient's positive right. For patients to die of their underlying condition, all we have to do is get out of death's way. For patients to die of something other than their underlying condition we have to do something to them. Oddly, although we generally refuse to recognize that patients have positive rights--which is why persons with chronic illnesses and disabilities fare so poorly in our healthcare system--we seem to think that the place to start granting patients their positive rights is with assisted suicide.

The basic difference between these two decisions, however, is this. The moment we started saving lives by deciding to use life-sustaining technology we put ourselves in the business of deciding when those lives would end. We cannot do the one without doing the other. Even Missouri and New York, strict though they are about the conditions under which it is permissible to allow treatment to stop, recognize that we have to be able to stop it sometime. Because we're in the life-saving business, we're in the life-ending business; it just comes with the territory.

That's just not so where assisted suicide is concerned. Our desire to use pain medications effectively does not force us to use them to shorten life. Because anesthesiologists are able to put patients to sleep (and wake them up again) does not ineluctably mean that doctors must be able to put them to death. The one just does not follow directly from the other.

Of all the myths that plague the assisted-suicide movement, none is greater than the myth that it advances the cause of patients' rights. Since neither suicide nor decisions to forgo life-sustaining treatment is against the law, the decriminalization of assisted suicide does not afford patients some legal protection that they do not already enjoy. The immunity it grants extends to doctors, not to patients or their families. Thus, the real beneficiaries of the legalization of assisted suicide are likely to be physicians, not patients.

After all, because patients are still in the position of requesting a physician's assistance, physicians still have the power and authority to decide whether they will or will not grant that request. The patient remains the suppliant, entreating the physician to render aid. The physician is free to deny this request, perhaps by saying that the patient is not competent or terminally ill, or by expressing doubts about whether the patient's choice is truly voluntary.

Think not? Then consider this. If we really wanted to give patients and families the power to make and act on this particular choice, we wouldn't force them to go through medical channels. Instead of passing a new law, we'd withdraw an old one--the law that prohibits anyone but a physician from authorizing the sale and purchase of narcotics, barbiturates, and other drugs. Mind you, I'm not saying that we should do that; I'm only saying that if the physician-assisted suicide movement were about empowering patients and families, that's what we'd be doing. Instead of taking death away from medical control, the physician-assisted suicide movement perpetuates and perfects that control. It perpetuates the rationalization and medicalization of death, by empowering physicians to act more effectively and efficiently than nature does where death is concerned and by subjecting the dying process to another layer of procedures.

Medical futility

Medical futility states a different starting premise from the one assisted suicide's advocates use, but ends up at the same place: the medicalization of death. Here the issue is not whether doctors may have the discretion to hasten death by adding something to the equation, but to hasten it by removing something from the equation. Oddly, they have to take different paths to reach the same result. But it's precisely because the paths are different that we can see what their common theme must be.

As in the case of assisted suicide, medical judgment about medically futile treatment is and will be varied, uncertain, ambiguous, subjective and value-laden. It will, in short, be anything but certain and unambivalent. Also, once doctors have the right to deny incompetent patient futile care, they will possess the right to deny competent patients futile care. Futility's advocates, like assisted suicide's, start with cases we are likely to consider the most sympathetic, thereby assuaging our concerns about other cas-

es, notwithstanding the legal implications that creating a new right in health care has for competent and incompetent patients.

Having seen where these movements are the same, we need to examine the differences. Whereas assisted suicide's advocates argue in favor of what is essentially a positive right, one of the cornerstones to the futility debate is that patients have no right to demand medical intervention. Moreover, assisted suicide's advocates portray patients as rational, understanding and clear-headed, while futility's advocates portray patients as emotional and incapable of understanding end-of-life decisions.

Thus, depending on whether what's being argued for is the right of physicians to render assisted suicide with immunity or to deny futile care with immunity, we are presented with a view of the world in which patients are or are not reliable arbiters of their fate and are or are not able to insist upon a medical intervention. The only perspective that reconciles this otherwise inconsistent view of patients is the belief that physicians should have the discretionary authority to determine how, where and when death occurs. If the ability to act with impunity is the ultimate index of social power, what the assisted suicide and medical futility movements are really about (regardless of what they claim and may otherwise be about) is medical power.

The snake chewing on its tail

To say that these movements are about medical power is not meant to suggest that they are the sole result of the medical profession's ongoing mission to preserve and extend its sovereignty. Although that's certainly part of the picture,[8] it's hardly the whole picture.

As a society we have so invested ourselves in the promise of medicine and have become such ardent believers in the ability of the humanity to control its destiny that we find it difficult to resist the arguments that assisted suicide's and futility's advocates make. After all, we're merely trying to improve on the dying process, by using medical science and technology effectively and efficiently to get us to a destiny we're naturally heading towards anyway. We're tidying up and streamlining a process that nature allows to occur in a random messy manner. To a society as enamored of technology and as obsessed with altering fate as ours is, altering the course of destiny is like altering the course of a river. The question isn't whether we can improve our condition, but, given that we can, how.

There's another aspect to these issues, however. The insistence that patients be able to enlist physicians to determine their fate through assisted suicide mirrors the insistence that physicians be able to deny patients medically futile treatment. Each is a demand for power, and each is made in a way that places it beyond deliberation. There is no question that patients must have the right to assisted suicide, and no question that doctors must have the right to deny patients medically futile care.

I suspect that the emergence of power politics in the area of death and dying and within the context of the physician-patient relationship occurs largely because of an erosion of trust. Patients feel that they have no reason to trust the medical or legal systems to allow them to die when death is at hand. They are afraid of ending up like Nancy Cruzan, whose dying was unnecessarily protracted. If they cannot trust the system to protect them, then they understandably want to make certain that they can command respect. Similarly, physicians feel that they cannot trust patients to make decisions about medically futile care. They fear that their wishes will not be respected, and that they will end up in a case like that of Helga Wanglie. Because they trust neither patients nor the legal system to respect them, they want to be in a position to call the shots when it comes to medically futile treatment.

Sadly, what physicians and patients really want is not so much to get their way as to be respected by one another for who they are. Neither patients nor physicians desire to run roughshod over one another. But because each so fears that the other is bent on doing just that, each is determined not to lose what has become a battle of wills.

What we see shaping up, then, is something like the ethical equivalent of the gunfight at the O.K. Corral. Patients and physicians are arming themselves with the best arguments they can find (and the best moral gunslingers they can persuade to join them) to make sure they'll be standing when the smoke clears. They seem to believe and to be saying to one another, "This physician-patient relationship isn't big enough for the two of us."

This development within the ethical community explains why the articles and conferences that focus on these issues have become increasingly shrill of late, and why the discussion of them frequently degenerates from a civil conversation into *ad hominem* attacks. It also explains why advocates of assisted suicide and of medical futility have taken their cause to courts. People go to court when they tire of conversation, when they've decided that winning is the only thing that matters, and when they've concluded that they cannot trust the other side to negotiate with them honestly and fairly.

As a former litigator and as someone who has been directly involved in the litigation of cases concerning capital punishment, abortion and life-sustaining treatment, I agree with those who find the current state of affairs to be both senseless and dangerous.[9] Once we conduct ourselves as if questions about which disagreement is likely to persist should be treated as if the answers to them are beyond deliberation, we undermine the democratic foundations of social collaboration. Once we decide that we need not tolerate another point of view, then it is fairly simple to decide that we need not converse with anyone whose opinion differs from our own. And once we decide that we need no longer converse, we commit ourselves at best to a shallow democracy, at worst to something that we may call democracy even though it is anything but that.

The great irony in all of this is that, in our quest for power through the rhetoric of rights and our insistence on winning through litigation, we lose

sight of what our European colleagues call "the power of conversation." As one American scholar has observed,

> The art of conversation is the art of finding language that is broad and novel enough to bridge conflicting perceptions of the world[.]
>
> Conversation enables us to know and even to understand one another, [even when] we do not like what we know and understand.[10]

If our understandings are to be shared, not imposed, if we are to regain the trust and respect that are essential to a civil society, then we must find a way to converse. As I said in the previous issue of *Trends*... (Volume 9, Number 1, Winter, 1994), the choice is a simple one: converse or perish.[11]

Having said that, let me add that my regard for the power and the necessity of conversation is neither sentimentalized nor Pollyannaish. While I think that it would be nice if we could just sit down and talk things over, I harbor no vision that the conversation will be pleasant; on the contrary, I suspect that it will prove inordinately difficult, partly because we are out of practice, partly because those who tend to speak the loudest are the least interested in allowing anyone else to be heard. Moreover, because power is unequally distributed within society and because some individuals and institutions have a vested interest in the distribution of power remaining just the way it is, I don't suspect that anyone is going to be open to the possibility of relinquishing that power, especially because power matters most in a society where trust and respect matter least.

I just don't think that we have any choice but to converse, difficult though that will be and futile though it will seem.

> The contemporary culture war is certainly a symptom of the loss of the languages of public morality in American society. Many of the battles of the culture war also represent a strain upon the course of democratic practice, a strain that could conceivably evolve into a serious threat to these traditions if the contenders become yet more polarized. These things being the case, the contemporary culture war also embodies both a challenge to understand more fully that which most deeply divides moral communities and an opportunity to reappropriate and invigorate the traditions of democratic experience.[12]

ENDNOTES

1. *Compassion in Dying, et.al. v. The State of Washington*, No. C94-119R (W.D.WA., May 3, 1994).

2. Bauman, Z *Mortality, Immortality & Other Life Strategies*. Stanford, CA: Stanford University Press, 1992.

3. Berger, PL & Luckman, T *The Social Construction of Reality*. New York: Doubleday, 1966: 101-102; Berger, P *The Sacred Canopy*. New York: Doubleday, 1967.

4. Ellul, J *Propaganda: The Formation of Men's Attitudes*. New York: Alfred A. Knopf, 1965.

5. Calabresi, G and Bobbit, P *Tragic Choices*. New York: Norton, 1978:70.

6. Zussman, R *Intensive Care: Medical Ethics and the Medical Profession*. Chicago, IL: University of Chicago Press, 1992: 116-138.

7. Bauman, Z *Freedom*. Minneapolis, MN: University of Minnesota Press, 1987.

8. Starr, P *The Social Transformation of American Medicine*. New York: Basic Books, 1982.

9. Hunter, JD *Before the Shooting Begins: Searching for Democracy in America's Culture War*. New York: Free Press, 1994; Hunter, JD *Culture Wars: The Struggle to Define America*. New York, Basic Books, 1991.

10. Barber, B *Strong Democracy: Participatory Politics for a New Age*. Berkeley, CA: University of California Press, 1984:186.

11. Bauman, Z *Legislators and Interpreters: On Modernity, Post-modernity and Intellectuals*. Ithaca, NY: Cornell University Press, 1987: 143.

12. Hunter, JD *Culture Wars, op.cit.* at 316-317.

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